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How accurate are witness descriptions of epileptic seizures?

JANNETH B. MANNAN & UDO C. WIESHMANN

The Walton Centre for Neurology and Neurosurgery, University of Liverpool, Liverpool, UK

Correspondence to: Dr Udo Wieshmann, The Walton Centre for Neurology and Neurosurgery, University of Liverpool, Lower Lane, Fazakerley, Liverpool L9 7LJ, UK. *E-mail*: wieshmann@vodafone.net

Problem: The diagnosis of epilepsy largely relies on the seizure description by a witness. Our aim was to assess the accuracy of seizure descriptions.

Methods: Twenty volunteers (10 medical students, 4 junior doctors working on a neurological ward and 6 non-medical students) viewed a video of a partial then secondary, i.e. generalised seizure, and were then asked to provide a written account of the event. The seizure had eight key features. Volunteers scored one mark for each described key feature. One mark was deducted for each false observation.

Results: The mean positive score was 3.5 (range 1 to 6). Unresponsiveness and lateralising features were often missed. The mean negative score was −0.8 (range 0 to −3). Erroneously described features included 'patient rolled over', 'agitated' or 'arms flopped about' as part of the tonic clonic seizure. Left and right were sometimes confused. The mean total score was 2.7 (range −2 to 6). A medical and a non-medical student achieved the highest scores, a doctor the lowest score.

Conclusions: The accuracy of seizure descriptions by witnesses was generally low and there were wide variations.

Key words: epilepsy; seizure description; witness account.

INTRODUCTION

Epilepsy is largely a clinical diagnosis based on the patient's history. Neurological examination, interictal electroencephalogram and neuroimaging can all be normal in patients with epilepsy. Making the correct diagnosis in patients with suspected epilepsy is often difficult. Around 20% of all patients in referral centres are incorrectly diagnosed as suffering from epilepsy[1, 2]. On the other hand, the diagnosis and treatment of epilepsy is often delayed[3]. In the majority of patients the diagnosis of epilepsy crucially depends on description of the attack by a witness but the accuracy of this important part of the diagnosis is largely unknown. The aim of our study was to assess the accuracy of witness descriptions.

METHODS

A video of a secondary generalised seizure with eight main features (Table 1) was shown to 20 volunteers (age between 20 and 30 years). Ten were medical students, 4 were junior doctors working on a neurological ward and 6 were non-medical students. Further information on the volunteers is provided in Table 2.

Table 1: Key features of the seizure.

Short duration (~3 minutes)
Eyes open
Aura (patient rings for nurse)
LOC (unresponsive when nurse comes in)
Head turning to left
Right dystonic posturing
Left unilateral gestural automatism
Followed by bilateral shaking

Development of methods to assess seizures

In a small pilot study, we showed a video of a complex partial seizure to a volunteer and asked the volunteer to complete a questionnaire, which had been previously developed and used Rugg-Gunn *et al.*'s criteria[4]. The volunteer was then asked for feedback. The

Table 2: Volunteer backgrounds and scores.

Volunteer no.	Volunteer background	Positive score	Negative score	Total score
19	Medical student, completed epilepsy teaching with seizure video	6	0	6
20	Non-medical student, seizures witnessed in the past	5	0	5
3	Medical student, completed epilepsy teaching without seizure video	4	0	4
6	Medical student, completed epilepsy teaching with seizure video	4	0	4
9	Medical student, no epilepsy teaching, seizures never witnessed	5	1	4
13	Junior doctor on neurological ward	4	0	4
17	Non-medical student, seizures never witnessed	4	0	4
18	Non-medical student, seizures witnessed in the past	4	0	4
1	Medical student, completed epilepsy teaching without seizure video	3	0	3
12	Junior doctor on neurological ward	3	0	3
8	Medical student, no epilepsy teaching, seizures never witnessed	2	0	2
10	Junior doctor on neurological ward	3	1	2
14	Non-medical student, seizures never witnessed	3	1	2
15	Non-medical student, seizures never witnessed	5	2	3
16	Non-medical student, seizures never witnessed	2	0	2
2	Medical student, completed epilepsy teaching, witnessed seizure	3	2	1
4	Medical student, completed epilepsy teaching with seizure video	2	1	1
5	Medical student, completed epilepsy teaching, witnessed seizure	4	3	1
7	Medical student, completed epilepsy teaching, witnessed seizure	3	2	1
11	Junior doctor on neurological ward	1	3	−2

Volunteers did not witness a real-life seizure unless stated in the table.

following problems were identified as a result of the pilot run: the volunteer had difficulties in interpreting the questionnaire terminology, the questionnaire failed to take into account the evolution of seizure, parts of the questionnaire were inappropriate for the seizure.

We, therefore, decided to use an open format, whereby volunteers were allowed to watch the seizure recording once and were then asked to provide a written account of the seizure immediately afterwards. Participants were asked to explain their observations in lay terms to clarify the intended meaning.

Developing a rating system

Observations were deemed to be clinically relevant, if the observation allowed (on balance) the classification of the seizure as epileptic (short duration, eyes open, unresponsive), if the observation suggested a partial onset with secondary generalisation (patient rings for nurse, is unresponsive when nurse comes in, asymmetrical motor phenomena, i.e. headturning, followed by bilateral motor phenomena), if the observation provided lateralising information (unilateral dystonic posturing, unilateral automatism).

Volunteers scored one point for each clinically relevant observation. A maximum of eight points could be obtained. For each incorrect observation one point was subtracted.

All witness accounts were scored independently by J.M. and U.W. to minimise bias that may be introduced by an individual marker. The allocated scores were then compared, and the agreement calculated[5]. The remaining statistical calculations were based only on the scores allocated by J.M.

RESULTS

Good agreement was found between scores allocated by J.M. and U.W. The limits of agreement between scores were from −1.182 to 1.162 points. Therefore, the score allocated by J.M. to a particular seizure description may be 1.182 points below or 1.162 points above the score allocated by U.W. Considerable differences were found to exist between individual seizure descriptions (Fig. 1). The mean positive score was 3.5 (range 1 to 6). Unresponsiveness and lateralising features were often missed. The mean negative score was −0.8 (range 0 to −3). Erroneously described features included ‘patient rolled over‘, ‘agitated’ or ‘arms flopped about’ as part of the tonic seizure. Left and right were sometimes confused. The mean total score was 2.7 (range −2 to 6). No volunteer achieved the maximum of eight points. Senior house officers and students who had received epilepsy teaching (‘professionals’) did not score consistently higher than non-medical students and medical students without epilepsy teaching (‘non-professionals’). Equally, there was difference in score by volunteers who had seen a seizure before and those who had not.

The volunteer scoring six points, was a medical student who had received epilepsy teaching and had seen a seizure on video before. There were another five medical students with the same background who all scored four points or less. The volunteer scoring five points was a non-medical student who had witnessed a number of real-life seizures when at school. A teacher

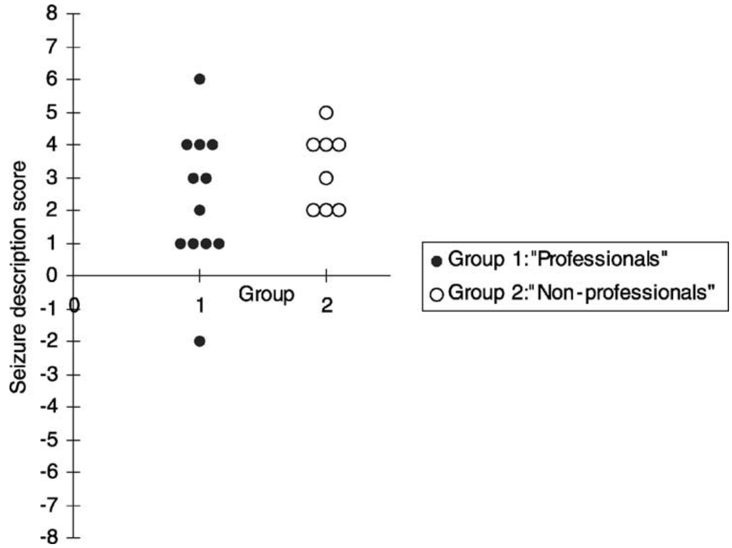

Fig. 1: Scatter-plot comparing scores obtained by those considered to be 'medical professionals' (i.e. doctors or medical students with epilepsy teaching), with those who were not.

had instructed the volunteer what to do in the event of the seizure. The volunteer scoring −2 points was a junior doctor, all junior doctors scored lower than average (mean score 1.75).

DISCUSSION

We developed a simple method to assess the accuracy of seizure descriptions. We used an open format instead of a questionnaire with closed questions. This approach had the advantage that the volunteers were free to record any memorised observation and were not guided by questions to give the correct answers. Another advantage was that we did not use any terms with potentially ambiguous meaning or meaning unknown to a volunteer. The disadvantage of the open format was that rating was more complex. To overcome this problem we developed a goldstandard for an accurate seizure description using generally accepted standards for the identification of epileptic seizures and seizure localisation, which were derived from studies using video-EEG telemetry[6–8]. Using this goldstandard, the descriptions were rated by two raters independently. A very good agreement between the raters was found indicating that rating open seizure descriptions was feasible.

Our study showed that the accuracy of seizure descriptions varied widely from volunteer to volunteer. Our study did not show any association between teaching and accuracy of seizure descriptions. This variation was difficult to explain. Different levels of intelligence are unlikely to account for the wide variation because all volunteers were successful students or doctors. Previous epilepsy teaching or working as a junior doctor on a neurology ward did not consistently improve the accuracy. There were some interesting individual results. The volunteer scoring six points, was a medical student who had received epilepsy teaching and had seen a seizure on video before. But five other medical students who had the same teaching failed to achieve high scores. Junior doctors score lower than average. Our findings suggest that the effectiveness of epilepsy teaching for medical students and junior doctors needs to be improved. The volunteer who achieved the second highest score was a non-medical student who had witnessed real-life seizures at school several years ago. This volunteer was instructed by the teacher what to do in the event of a seizure. Seizures are frequent and many people will sooner or later witness a seizure. Raising the awareness for seizures and instructing people what to do may improve the management of the seizure but also the subsequent description for the doctor.

Our finding that seizure descriptions were often incomplete was in keeping with a study by Rugg-Gunn *et al.* who used a questionnaire[4]. Using an open approach instead of closed questions, we revealed that the description was not only incomplete but that there were also false memories. In some cases 'agitation' and 'flopping' which were clearly not present were falsely remembered. These false memories could have lead to an erroneous diagnosis of non-epileptic seizures. False memories are common. The reasons for false memories are not entirely clear but semantic processing or confusion between memories for perceived and imagined events may lead to the creation of false memories[9, 10].

Our method of measuring the accuracy of seizure descriptions had, out of necessity, some limitation. Witnesses who observe a seizure in real life are under considerable stress and often assess vital function or alert emergency services which all interferes with their ability to accurately describe the seizure. These potentially important factors were not simulated in our method. Nevertheless, our study showed that the accuracy of seizure description varies widely.

Our finding that the accuracy of witness descriptions varies widely has important clinical implications. The diagnosis of epilepsy, and subsequent classification of seizure type, has far reaching consequences for the patient, affecting almost all aspects of life. The classification also affects the choice of antiepileptic drugs. Drug treatment is usually prolonged. Inappropriate choice of medication can cause seizures to become worse. Antiepileptic drugs are well known for their side effects[11]. Misdiagnosis and prescription of unnecessary or incorrect medication is, therefore, unacceptable. The witness account is a key element in the diagnosis of epilepsy in most patients. This applies for the traditional clinical situation and semistructured interview or questionnaires[12,13]. Neither technique can overcome the problem of false memories of witnesses. Doctors need to make an assessment of the witness' ability to describe seizures accurately. Taking the history repeatedly and from different witnesses, the use of handheld camcoders[14] and the use of video-EEG telemetry[6] may all help to reduce the risk of misdiagnosis because of inaccurate witness descriptions.

In summary, our study showed that the accuracy of seizure descriptions—including the description by medical professionals—was highly variable.

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